

STATE & NATION

Chronic fatigue renamed, diagnosis clarified

Unrefreshing sleep, 'brain fog' are symptoms

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Associated Press

WASHINGTON, D.C. —

Doctors are getting a new way to diagnose chronic fatigue syndrome — and influential government advisers say it's time to replace that hated name, too, to show it's a real and debilitating disease.

The Institute of Medicine on Tuesday called on doctors to do a better job diagnosing an illness that may affect up to 2.5 million Americans, and it set five main symptoms as the criteria.

And the IOM's choice of a new name — Systemic Exertion Intolerance Disease, or SEID — reflects a core symptom, that exertion can wipe patients out.

"This is not a figment of their imagination," said Dr. Ellen Wright Clayton of Vanderbilt University's

Center for Biomedical Ethics and Society, who chaired the IOM panel. "These patients have real symptoms. They deserve real care."

Here are some things to know about the disorder:

WHATEVER IT'S CALLED, WHAT IS THIS ILLNESS?

Its hallmark is persistent and profound fatigue where, on a bad day, a simple activity like grocery shopping can put someone to bed. It's often accompanied by memory problems or other symptoms.

Laura Hillenbrand, author of best-sellers "Unbroken: A World War II Story of Survival, Resilience, and Redemption" and "Seabiscuit: An American Legend," has put a public face to the confusing illness.

"Well, in the years in which I've been exhausted it's been something where I've had to drag myself to my computer or to my telephone to do interviews," she said on CBS' "Face the Nation" last December.

While working on her book "Unbroken," she said that over a two-year stretch, she was "unable to leave the house a single time, because I simply wasn't strong enough to walk to the car to get out of the house."

GETTING DIAGNOSED HAS LONG BEEN A PROBLEM

Between 836,000 and 2.5 million Americans suffer from the disorder, and most have no formal diagnosis, Tuesday's report estimated.

Patients flooded the IOM with stories of years of misdiagnosis or even being dismissed by skeptical doctors as having a psychological problem instead.

There's no medical test for the disorder, leaving doctors to rule out other possible causes for the exhaustion.

No one knows what causes it.

There's no specific treatment, and the IOM found less than a third of medical schools teach about the disease.

WHAT'S NEW

The federal government asked the independent Institute of Medicine to investigate the state of chronic fatigue diagnosis. Tuesday, the panel issued new criteria that it said should enable any physician to tell which patients are affected.

Diagnosis requires three core symptoms: Fatigue and reduction in pre-illness levels of activity that last for more than six months, the post-exertion worsening, and sleep that is unrefreshing despite exhaustion.

Also, patients must have at least one other symptom: Cognitive impairment, sometimes described as "brain fog," or what's called orthostatic intolerance — meaning symptoms improve when lying down and patients find it hard to stay upright for long.

WHAT'S IN A NAME?

Patients have long sought a change to a name they say

belittles their suffering. Some groups already had begun using a more tongue-twisting name — myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS.

Tuesday's report rejected that option, saying not all patients have the muscle pain and brain or spinal cord inflammation that medical jargon reflects.

It's too early to know if the alternative name proposed Tuesday will catch on. But just including the word "disease" instead of "syndrome" is important, said Carol Head, who leads the Solve ME/CFS Initiative, the largest advocacy organization.

"Having called this serious disease by an inappropriate and frankly insulting name is one of the factors that kept doctors, friends, family members, even employers from affording it the seriousness it deserves," she said.

WHAT TO DO AFTER DIAGNOSIS

Doctors may not know how to cure the disorder, but there are treatments for individual symptoms, noted committee member Dr. Lucinda Bateman of the Fatigue Consultation Clinic in Salt Lake City.

Moreover, the IOM said there's been "a paucity of research" into the causes, treatments, even the natural history of the disease to figure out who may get better over time. At Solve ME/CFS, Head said the report should spur more research funding.

WHAT HAPPENS NEXT?

The IOM advised the government to develop a toolkit to help doctors diagnose the disease, and to make sure the disorder is assigned a specific medical billing code. The government is reviewing the recommendations.

Committee members are spreading the word about the diagnostic criteria in medical journals, and the institute's web site, www.iom.edu, eventually will post a physician guide.